

# LIVING WELL WITH CHRONIC ILLNESS



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## Coping With Chronic Illness

More than 90 million Americans live with some form of a chronic illness, such as cardiovascular disease, cancer, lung disease, arthritis and diabetes. A chronic illness is a medical problem that lasts a year or longer, limits what a person can do, and requires ongoing care. The course of illness and level of disability from chronic diseases varies widely. Some have mild but manageable discomfort and few physical limitations. Others have persistent and debilitating pain and decreased quality of life.

### Diagnosis and adjustments

With diseases such as cardiovascular or lung disease, while very serious, the diagnosis and treatment is relatively straightforward. However, with conditions such as autoimmune disorders, thyroid disease, chronic fatigue or multiple sclerosis, the diagnosis is anything but straightforward. It can take months or even years for an accurate diagnosis and viable treatment plan.

When a diagnosis is made, an individual must adjust to the realities and demands of the illness and the treatments. When illness or treatment interferes with a person's mobility and independence, feelings of despair, loss and sadness are normal. They are usually resolved by family support and encouragement. However, in many instances chronic illness is associated with the onset of depression.

### Self-efficacy

Self-efficacy is a belief that one has the capabilities to execute the courses of actions required to manage her life. As an illness becomes more debilitating the ability to function independently wanes and self-efficacy decreases. Low self-efficacy is associated with depression in those with chronic illness.

### Depression

Any chronic condition can trigger depression, but the risk increases with the severity of the illness and the level of life disruption it causes. Approximately 25 percent to 33 percent of individuals with a chronic condition will become depressed, significantly higher than the general population.

The rate for depression occurring with chronic illness is quite high. For example:

- **heart attack:** 40 percent to 65 percent
- **coronary artery disease (without heart attack):** 18 percent to 20 percent
- **Parkinson's disease:** 40 percent
- **multiple sclerosis:** 40 percent
- **stroke:** 10 percent to 27 percent
- **cancer:** 25 percent
- **diabetes:** 25 percent

Depression often aggravates the illness, especially if the illness involves pain or fatigue or disrupts social and family functioning. Depression can also intensify pain and cause fatigue that can worsen the loss of energy associated with chronic medical conditions.

### Trusting your medical providers

Millions of people who cope with chronic illness are faced with agonizing decisions every day. And they may struggle with a health care system not designed to meet their medical needs or provide necessary information or adequate support.

Having a chronic condition almost always requires many visits to doctors and clinics. Believing in the competence of the medical team can provide much needed peace of mind. The concept of patient and

family-centered care is essential in modern medical practice but even more important in managing chronic illness. It is important that you feel comfortable with your care provider.

### **Learn about your condition**

Access to medical information has never been greater. There are countless professional medical resources available on the Web and through your health care provider. Ask your doctor where you can learn more about your condition. Learning about your illness allows you to collaborate with your doctor and take an active role in your treatment. Don't be afraid to ask your doctor questions.

### **Emotional and spiritual support**

Having family and social support improves the perceived quality of life for individuals with chronic conditions. Even during the darkest hours of an illness, just knowing that someone cares and that you are not alone can make all the difference in the world. Nontraditional approaches to illness—including prayer, meditation, relaxation, medically-approved exercise and rhythmic breathing—have been shown to lessen the intensity of some symptoms and improve quality of life.

If you or a family member has a chronic condition, take heart because you are not alone. Ask for help and support from family members, friends or clergy.

By Drew Edwards, EdD, MS  
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## The 'Gifts' of Living With a Chronic Illness

When you are living with a chronic illness, you probably experience many challenges. Not only are there physical burdens, there are also emotional and spiritual challenges, work issues, financial stresses and health insurance obstacles. However, if you must live with an illness, there are hidden gifts that the experience of chronic illness offers. Consider a few of these gifts of perspective that can come from living with chronic illness:

- **You know the difference between important and not important.** The small things that may throw other people off course may feel like nothing to you. Caught in traffic? No big deal. The house is messy? No big deal. When something is important it gives you pause, but the rest is almost easy to shake off because you know life is of great value.
- **You realize your own mortality.** We will all face death. Some of us are more connected with this fact because we must exert so much effort and energy and faith in staying alive. You know you must live your life now. There will come a day when you may not have the same abilities you have now. Illness provides an inner voice that reminds you life is yours to grab hold of now.
- **You are able to relish the present moment.** Not only do you realize death is a reality, but you can use that awareness to put your energy into the current moment. It's easy to get depressed about the past or anxious about the future. Illness can magnify these experiences. Eventually, however, illness teaches you to be present right now in this very moment. This moment is all we ever have. We learn this and we begin to live it.
- **You may be more direct and more communicative with those you love.** If you have children, for instance, you may make a point of demonstrating and expressing how much you love them, knowing you may not be able to nurture them in this life in the same way or as long as you had hoped. In one way, children are the essence of who we are after we are gone. In illness, we know how important it is to express and demonstrate the love we have to offer.
- **You find strength in giving yourself credit for surviving.** You are surviving every minute you live with your illness. You are learning about endurance. You are learning about faith. You are learning about your inner strength, your capacity to keep going, keep trying and keep hoping.
- **You may feel more connected to the people in your life, in a deeper, more significant way.** Relationships have a way of growing when illness erupts. People are now able to reach out in ways that show you they care. You may also realize that if you had never gotten sick, you may have never experienced this level of support and love from a community or group of friends and family members. The feeling of being cared about by others is life-enriching. Let your gratitude flow outward from you to those who have offered care and concern to you.

### What if I know these gifts are possible but I feel only despair?

Depression is very common in people who live with a chronic illness. If you notice that you are feeling hopeless and helpless, are not sleeping or eating well, or are feeling unable to make decisions or problem solve, seek help from a mental health resource in your area. You are not alone. There are others out there living with your condition, whether it's multiple sclerosis, diabetes, epilepsy, cancer, rheumatoid arthritis or another condition. Many organizations exist to help and support you through the challenges.

### What can I do to explore these gifts more?

Ask yourself what you wish you had been told at the start of your journey with a chronic illness. Could you provide that to help someone else who has just received a new diagnosis? As you learn about your specific difficulties it can help to remind yourself of your own strength, of your growing insight, of the people you love and who love you. You really are made stronger by facing adversity. This is a gift. Perhaps not one you wanted, but it has arrived.

By Rebecca Steil-Lambert, MSW, LICSW, MPH  
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## Don't Let a Chronic Health Condition Harm Your Marriage

Marriage always takes skill and hard work. When one person is permanently injured or develops a chronic health condition, it takes even more, but a good marriage is worth the effort.

### Your marriage, tested

You may have promised to be there for each other in sickness and in health, but you might not be ready for the strain and emotional wear a chronic illness or a disabling injury can have on your relationship. Psychiatrist Scott Haltzman says chronic illness will test a relationship. It will force you to rethink who you are, reorganize your daily life and reorder your priorities.

If your partner was a runner, he or she might need time adjusting to a new self-image after a disabling stroke. *Be patient.*

If the family nurturer has developed lupus, he or she needs the nurturing now. *Be kind.*

While you adjust to the situation, keep your marriage alive by communicating. *Talk, talk, talk* to each other, but *also listen* carefully to what your partner says.

Some people are overwhelmed by a partner's illness, and might want to flee. Men tend to be action-oriented, so it can be hard for them to picture themselves caring for another person's physical needs, Haltzman points out. *Be understanding.*

On the other hand, unaffected partners can find inner resources, emotional strength, character and resourcefulness they never knew they had, until they were put to the test.

Psychiatrist Eva Ritvo advises couples facing chronic health problems to remember their values and their vows, formal or not.

### Tips for couples

- **Read up on the illness or disability.** The more you know, the better. Go to respected sources, such as the Centers for Disease Control and Prevention or the National Institutes of Health.
- **Have a heart-to-heart conversation with your partner.** Discuss how much of your old life you can keep and what will change. Lay out the facts. Will this change your income? The way your home is set up?
- **Adjust your activities as needed.** Chronic illness might keep you from doing some things you always did together. If you bowled as a couple, can the healthy person still do it? Are there new activities you could try together?
- **Be open and ready to learn new skills.** Household roles may change. You may need to learn to cook or shop or take care of the car.
- **Take good care of yourself.** You will need to be strong while you learn new ways.
- **Say goodbye to whatever you are giving up and hello to your new life together** in a special way, suggests therapist Tina Tessina. Celebrate change and your love for each other.
- **Strive to keep the physical aspects of your love alive.** Be open to change, and you will find ways to show your love, advises self-help author Elaine Fantle Shimberg.

### Tips for caregivers

- **Work to maintain your own health and energy.** You may find yourself exhausted at first. This is normal. It will get better.
- **Strategize with your partner for ways to make your life easier.** Accept what is, and know even that will change.



- **Allow yourself to have help.** Take a day off. Let someone else do a chore.
- **Find a caregiver support group,** in your community or online.

#### Tips for the afflicted partner

- **Start the conversation about how the two of you can best minimize the impact of illness** on your marriage.
- **Accept your physical changes.** Some sadness and anxiety are normal. As your life changes, you may go through all 5 stages of grief—denial, anger, bargaining, depression and acceptance.
- **Don't hide behind alcohol, recreational drugs or bad behavior.** Give yourself a chance to learn to tolerate the situation.
- **Acknowledge your strength and limitations.** Try to function as normally as possible. Use physical therapy or other means to build muscle strength.
- **Avoid negative language,** even in jest, says therapist Dorothea Hover-Kramer.
- **Involve your caregiver** in medical decisions.
- **Care for the caregiver.** Give your partner time to be alone or pursue some outside activity.
- **Be patient with yourself** as you go from one situation to another.
- **Seek out and accept support from family, friends and clergy.** Look for advice from recognized disease-specific organizations, such as the Arthritis Foundation or American Lung Association.
- **Show appreciation.** Make a point of focusing on things you're happy for, every day.

By Paula Hartman Cohen  
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## Talking With a Child About an Adult's Chronic Illness

### What can make it easier to talk?

Seize the right moment. Sometimes it is best to wait until a child asks a question or comments about a change. For instance, "Mommy, why do you sleep all the time?" While your immediate response might be to snap back that you are tired, you may want to use the moment to help the child understand what is going on in a matter-of-fact way. As long as you can keep your composure, try to provide clear simple reasons you might need sleep.

Match what you say to the age of the child. Whether questions are about you or another adult in a child's life, it is best to be honest and choose appropriate amounts of information.

### Keep information simple

- **Explain in terms they can understand.** For example: "I know it seems like Daddy is sleeping a lot these days, and I want to help you understand what happens with me that I need so much sleep. I know that when you are young and very healthy it is hard to imagine feeling sick or wanting to take lots of naps. However, do you remember when you had that stomach bug last year, and felt like you needed to be in bed for a few days? My illness is like that sometimes, where my body is under extra stress and needs to rest a lot, especially after I have a busy day."
- **With very young children, be careful to keep your explanation of illness or treatments simple.** For example, "I need this medicine so I can feel well and be your mommy."
- **Use children's books to read about the body and the jobs of all the organs.** Incorporate an explanation of your illness. For example: "The pancreas makes insulin, which allows the food you eat to give you energy. Daddy's body doesn't make insulin, so instead he takes shots."

### What about the really hard times?

With chronic illness there may be times that are scary and times that seem more normal for a child. After a scary moment, try to normalize the event as best as possible. For example:

- "The ambulance came because it's the fastest way to get to the hospital where there are lots of doctors and nurses to help people that don't feel well."
- "Grandma is sick to her stomach because the medicine she takes to get well sometimes makes her nauseous. It's unpleasant for her, but most people who take the same medicine have the same response and they feel sick just like Grandma. That's one of the reasons she needs our love and attention right now."

### What else might be helpful?

- **Let the child help.** Children like to feel like there is something they can do to help. Children ages 6-11 can be asked to help in small, meaningful ways, such as creating art, making toast, getting slippers, watering plants or feeding a pet. Children 12 and older can take on bigger tasks and responsibilities.
- **Understand that there are variable responses to illness issues.** Be prepared for anger, sadness, and, sometimes, inappropriate laughter. All of these reactions are possible. Asking what the child is thinking or feeling can provide insight into what is going on emotionally.
- **Don't provide overly eager reassurances,** as this may trigger more fear than a child actually has to begin with. It may not have occurred to a child that the ill person would not be just fine.
- **Be available to hear a child's expression of grief, fear, anger and sadness.** Validate these feelings as real and difficult. Chronic illness is often marked by progression of a disease, or decline in functioning. Children will have times when they are more aware of the illness than other times. Let the child know you are available to talk about any question or concern that comes up.



- **Provide outlets.** Ask the child if he would like to take an art class, read a book about the illness, or become active in a campaign to raise money for cure research.
- **Engage your community.** Think of your neighbors, friends, extended family and any groups you belong to as cushioning for the emotional impact of chronic illness. If it's a parent who is sick, the child needs to know that there are other trusted adults who can take care of her and talk to her. Include the child in conversations about the helpfulness and reliability of other adults around her.

"Familiarity with illness, disappointed hopes, sudden crises, adults who cry or explode in anger is excellent preparation for an imperfect world. And such a childhood need not be cheerless..."

—Cheri Register, from her book *Living with Chronic Illness*

By Rebecca Steil-Lambert, MSW, LICSW, MPH  
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## Small Changes Can Improve Life With an Ongoing Medical Condition

Millions of people have learned to cope with conditions that do not go away—including diabetes, arthritis, high blood pressure, asthma and even depression—by making changes in the way they live, day to day.

### Getting the most out of your life

Here are a few tips for getting the most out of your life, even if you live with an underlying health problem:

- **Eat only healthy food.** Stay away from fast food, greasy, sugary or processed food, including powdered sauces and boxed or instant food mixes. Eat as many fresh fruits and vegetables as possible—the more colorful the better.
- **Get your weight as close to normal as possible.** Work hard to bring your weight to an ideal point designated by your doctor or a trusted medical source. You put your heart and respiratory system under unnecessary stress when you force them to work against extra weight, or if you deprive them of whatever they need to perform at optimum rate. Be kind to your body. Think about every spoonful of food you eat, and you may find yourself eating less. If you need to gain weight, add pounds by eating good food, not high-calorie junk.
- **Exercise.** Don't go overboard, but you should be doing something every day or every other day.
  - *Walking is good*, but if you have the strength to do more, join a gym with trainers who can help you set up an appropriate exercise program.
  - *Look for ways to add activity into your day.* Take the stairs instead of the elevator. If you have time, park in a distant spot and walk to where you are going.
- **Go outside every day.** Sun and fresh air do wonders for your body and your mood. A breath of fresh air is a priceless, painless and readily available remedy for the blues, and more.
- **Take naps.** Listen carefully to your body. If it tells you it needs more rest, heed that advice.
- **Don't smoke.** Drink very little alcohol, if any. Your body is already busy keeping an ongoing medical condition in check. Don't make it work harder by adding toxins to the mix. If you drink at all, make it something light and small. Save it for special occasions.
- **Find something positive to do with your spare time.**
  - *Learn to play an instrument.* Volunteer for your favorite charity. Anything you can do to focus on the future is a good thing. Activity takes your mind off your troubles and lets you accomplish something to be proud of.
  - *Add soothing activities to your life.* Listen to music. Surround yourself with beauty.
  - *Follow your bliss.* Put yourself in situations that bring you peace and happiness. Maybe they are places, or perhaps activities. Find what captures your imagination and spirit, and put that energy to work for you.
- **Reduce stressors.** Exercise caution in advance of whatever you do to reduce the risk that something will go wrong. Everything you can do to reduce stress helps.
  - If necessary, change jobs, move to another place or stay away from toxic relationships.
  - Check your tires, oil and brakes often.
  - Learn to use the mute button on your television and telephones.
- **Be grateful for what you have.** You may have a chronic condition, but it could be worse. Be thankful that your health problem is under control. Research at several major universities shows that people who are grateful for what they have in life—and express it—are healthier, happier and more successful in relationships than those who do not. So count your blessings.
- **Educate yourself.** Learn as much as you can about your body, and use that information. Arm yourself with as many tools as possible so you can make good decisions when you need to. With guidance from a trustworthy source (a physician or a disease-specific support/research organization), you should be able to face any crisis that comes along with confidence.

By Paula Hartman Cohen  
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## Resources

Your local hospital for local support groups

### Print resources

*Eat, Drink, and Be Healthy: The Harvard Medical School Guide to Healthy Eating* by Walter C. Willett, M.D. Free Press, 2005.

*How to Help Children Through a Parent's Serious Illness* by Kathleen McCue with Ron Bonn. St. Martin's Press, 2011.

*Raising an Emotionally Healthy Child When a Parent Is Sick* by Paula Rauch and Anna Muriel. The McGraw-Hill Companies, 2005.

*Savor: Mindful Eating, Mindful Life* by Thich N. Hanh and Lilian Cheung. HarperOne, 2011.

*The Secrets of Happily Married Men: Eight Ways to Win Your Wife's Heart Forever* by Scott Haltzman and Theresa Foy DiGeronimo. Jossey-Bass, 2007.

*The Secrets of Happily Married Women: How to Get More Out of Your Relationship by Doing Less* by Scott Haltzman and Theresa Foy DiGeronimo. Jossey-Bass, 2008.

*The Secrets of Happy Families: Eight Keys to Building a Lifetime of Connection and Contentment* by Scott Haltzman. Jossey-Bass, 2009.

*When Someone You Love Has Cancer: A Guide to Help Kids Cope* by Alaric Lewis. Abbey Press, 2005.

### Internet resources

American Lung Association, [www.lungusa.org/](http://www.lungusa.org/)

Arthritis Foundation, [www.arthritis.org/](http://www.arthritis.org/)

Cancer Support Community, <http://www.thewellnesscommunity.org/>

Centers for Disease Control and Prevention, [www.cdc.gov](http://www.cdc.gov)

Centers for Disease Control and Prevention National Center for Chronic Disease Prevention and Health Promotion. "About Chronic Disease," [www.cdc.gov/nccdphp/about.htm](http://www.cdc.gov/nccdphp/about.htm)

MedlinePlus®, <http://www.nlm.nih.gov/medlineplus/>

National Institutes of Health (NIH), <http://health.nih.gov/>

The National Multiple Sclerosis Society, <http://www.nationalmssociety.org/>

The Robert Wood Johnson Foundation. Partnership for Solutions. "Better Lives for People with Chronic Conditions," [www.chronicnet.org](http://www.chronicnet.org)

Wonders & Worries: A Family's Illness, a Child's Journey, <http://www.wondersandworries.org>